

HEALTH CARE POLICY AND LAW

The Treatment of Patients With Unbearable Suffering— The Slippery Slope Is Real

Diane E. Meier, MD

Physician-assisted death (PAD) is now legal in 9 US states and the District of Columbia and is under consideration in 17 more.¹ Legalization generally follows ballot, as opposed to legislative, initiatives in the setting of extensive marketing



Related article

efforts by advocacy groups focused on convincing the public that they face a future of unbearable suffering if PAD is not available. Whereas fear of unbearable suffering at the end of life is a commonly expressed concern, most Americans should be able to expect reliable and expert relief of suffering as a result of medical advances in geriatrics and palliative care. The fact that the public is so easily persuaded at the ballot box that suffering is inevitable and that they cannot trust the health care system to be responsive to their suffering should give us pause. The report by van den Berg et al² in the current issue of *JAMA Internal Medicine* of 53 cases of PAD or euthanasia in the Netherlands with unbearable suffering attributable to multiple geriatric syndromes should cause alarm.

Existing PAD laws in the US contain fairly strict safeguards, requiring that the patient have a terminal illness (is likely to die within 6 months) and intact decisional capacity, and that there be no evidence of coercion from family or others or evidence of depression or other psychiatric disease. In contrast, countries where PAD has been legal for considerably longer than the US have revised their original laws to remove prognostic requirements, eliminate psychiatric exclusions, broadly define unbearable suffering (to include such conditions as geriatric syndromes and existential distress), and reduce reporting requirements. For example, in the Netherlands, physicians must now follow only vague due care criteria before administering euthanasia or physician-assisted suicide (EAS). Only 75% of EAS cases are reported to regional euthanasia committees as required by law, and nonreporting is rarely punished,³ and EAS in children, people with mental illness, and dementia further illustrates the impossibility of limiting the practice and safeguarding vulnerable patients once it is permissible.^{4,5} The study by van den Berg et al² points to expansion of EAS to another, potentially very large, group of eligible patients: those with multiple geriatric syndromes.

Between 2013 and 2019, a total of 1605 occurrences of EAS in people with multiple geriatric syndromes were recorded in the Netherlands, accounting for 4% of all EAS cases in that period. We can assume this number is an underestimate given the level of failure to report. We know little about the 53 cases described by the regional euthanasia committees as represen-

tative. Seventy-seven percent were women and older than 90 years, and approximately 1 in 10 was described as having gloomy or depressive feelings. No information on cognitive or functional capacity is given, no psychiatric evaluation is described for any patient, no information on family or physician efforts to identify remediable issues or to provide support and encouragement is given, and the possibility that perceived or actual burdens on caregivers motivated the requests is not considered.

Although the case studies acknowledge remediable sources of distress, such as falls, loneliness, social isolation, and fewer life pleasures, the only intervention offered appears to be an assisted death. Does the (quick, easy, and inexpensive) option of EAS reduce the medical profession's responsibility to advocate for the continued value of the patient's life? It is inarguable that both time and money are scarce in health care, both globally and in high-income nations. How should we think about the balance of benefits and burdens of easier access to PAD in the current context of the increasing numbers of older persons, increasing income inequality and poverty, resource stresses on families and health systems, and the already well-documented inadequacy of government-funded health care⁶ in ensuring high-quality medical care for older persons in our society? Will legal access to PAD serve as a quick, easy, and inexpensive means of handling the needs of an increasing aging population here and around the globe?

Proponents argue that access to PAD supports the autonomy of individuals who have concluded that death is preferable to the burdens of their continued life. Most healthy Americans have favored legalized PAD in polls.⁷ As with any public policy, however, potential benefits must be weighed against societal harms. The expansion of eligibility criteria and the failure of the initial regulatory constraints to contain PAD to a narrowly defined and small group of patients demonstrated by the study underscore real societal harms in the Netherlands and the potential for such harms in the US. Once access to PAD becomes legal, when does a right become an obligation, especially when families are strained and society denies patients and families the resources needed to receive safe and reliable care? The more than 50 000 nursing home deaths from COVID-19 have exposed the lack of investment and years of underfunding in the care and safety of our most vulnerable adults.

Requests for PAD may result from many modifiable stressors.⁸ Depression is frequently a concomitant component of requests for a hastened death and is routinely under-

diagnosed and undertreated⁹ despite the availability of effective therapies. Pain is underrecognized and undertreated in people of all ages but is especially prevalent among the oldest old¹⁰ and was reported in 41 of 53 of the cases in the series reported by van den Berg et al.² Regulations on PAD assume that practitioners have both the training and the time to carefully explore the meaning of the request with patients and families, to understand the sources of the despair, to offer and try alternative approaches to reduce suffering, to be present during that suffering, and to provide encouragement and validation to the patient regarding the value and meaning of their continued life. Most do not.¹¹ The epidemic of loneliness and social isolation among older persons further threatens society's ability to surround its citizens with care, attention, and human support.

Permissive access to PAD in this social context comes close to societal validation, supported by policy, that some lives are no longer worth the investment required to preserve them—the implicit belief that both the individual and the society would be better off if the patient were dead. This is precisely the type of thinking that led first to the 1927 US Supreme Court's 8 to 1 decision to uphold a state's right to forcibly sterilize persons considered unfit to procreate, then to the German physicians' advocacy of and participation in the eugenic sterilization policies of the early 1930s, and finally to Germany's involuntary euthanasia of those “lives unworthy of life”—

children with disabilities beginning in 1939 and aged people and people with disabilities beginning in 1940.

Fear of aging-related illness, dementia, and functional decline is widespread, and physicians are not immune to these fears. Indeed, surveys consistently demonstrate that physicians consider profound debility or cognitive impairment to be fates worse than death. In contrast, diverse older people living with age-related disability rate their own quality of life as fair to very good and point to preservation of dignity and a sense of control as key enabling factors.¹² Physicians' fear of their own futures, as exemplified by the patients they treat, may result in the unconscious projection of support for a hastened death. The growth in the fields of geriatrics and palliative care exist precisely to help reduce suffering, ensure dignity, and restore control, with the goal of helping patients and their loved ones regain a quality of life that makes life worth living.

Patient despair and suffering should be met with human connection and support to relieve suffering and improve quality of life, not a rush to put an end to things to reduce collective distress at the confrontation with finitude. David Barnard wrote, “The sting of illness and death is the specter of broken relationships and the loss of the world. Over and against this threat stand the efforts of caregivers and companions to embrace the sufferer and continuously reaffirm his or her capacity for relationship.”^{13(p 26)} Meaningful and committed human connection—not 2 g of secobarbital—is the right prescription.

ARTICLE INFORMATION

Author Affiliation: Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, New York, New York.

Corresponding Author: Diane E. Meier, Department of Geriatrics and Palliative Medicine, Icahn School of Medicine at Mount Sinai, One Gustave Levy Place, Box 1070, New York, NY 10029 (diane.meier@mssm.edu).

Published Online: December 7, 2020.
doi:10.1001/jamainternmed.2020.6884

Conflict of Interest Disclosures: None reported.

REFERENCES

1. In Your State. Compassion & Choices website. 2019. Accessed September 8, 2020. <https://compassionandchoices.org/take-action/in-your-state>
2. van den Berg V, van Thiel G, Zomers M, et al. Euthanasia and physician-assisted suicide in patients with multiple geriatric syndromes. *JAMA Intern Med*. Published online December 7, 2020. doi:10.1001/jamainternmed.2020.6895
3. Preston R. Death on demand? An analysis of physician-administered euthanasia in The Netherlands. *Br Med Bull*. 2018;125(1):145-155. doi:10.1093/bmb/ldy003
4. Evenblij K, Pasman HRW, van der Heide A, Hoekstra T, Onwuteaka-Philipsen BD. Factors associated with requesting and receiving euthanasia: a nationwide mortality follow-back study with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age. *BMC Med*. 2019;17(1):39. doi:10.1186/s12916-019-1276-y
5. Bollen JAM, Ten Hoopen R, van der Hoeven MAHBM, et al. Organ donation after euthanasia in children: Belgian and Dutch perspectives. *Arch Dis Child*. 2019;104(9):827-830. doi:10.1136/archdischild-2018-315560
6. Ouslander JG, Grabowski DC. COVID-19 in nursing homes: calming the perfect storm. *J Am Geriatr Soc*. 2020. Published online July 31, 2020. doi:10.1111/jgs.16784
7. Wood J, McCarthy J. The majority of Americans remain supportive of euthanasia. *Gallup News*. June 12, 2017. Accessed September 8, 2020. <https://news.gallup.com/poll/211928/majority-americans-remain-supportive-euthanasia.aspx>
8. Quill TE. Doctor, I want to die. Will you help me? *JAMA*. 1993;270(7):870-873. doi:10.1001/jama.1993.03510070092043
9. Kok RM, Reynolds CF III. Management of depression in older adults: a review. *JAMA*. 2017;317(20):2114-2122. doi:10.1001/jama.2017.5706
10. Domenichiello AF, Ramsden CE. The silent epidemic of chronic pain in older adults. *Prog Neuropsychopharmacol Biol Psychiatry*. 2019;93:284-290. doi:10.1016/j.pnpbp.2019.04.006
11. Farber S. Living every minute. *J Pain Symptom Manage*. 2015;49(4):796-800. doi:10.1016/j.jpainsymman.2015.02.002
12. Romo RD, Wallhagen MI, Yourman L, et al. Perceptions of successful aging among diverse elders with late-life disability. *Gerontologist*. 2013;53(6):939-949. doi:10.1093/geront/gns160
13. Barnard D. The promise of intimacy and the fear of our own undoing. *J Palliat Care*. 1995;11(4):22-26. doi:10.1177/082585979501100405